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Nursing Considerations in the Assessment of an Autistic Child

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Nursing Considerations in the Assessment of an Autistic Child

By Leanna Walker

A thesis for Western Kentucky University's

Honors Program

Fall 2001

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Dedications and Acknowledgements

This thesis is dedicated to an amazing four-year-old boy with a bright future and his faithful and supportive mother. Without them, this project would not have been possible.

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Abstract

A comprehensive assessment is essential for creating a nursing care plan for a child with autistic disorder. A standardized tool provides a guide for gathering assessment data; however, the method of assessment must be individualized to each patient. The nurse's role in planning care for a child with autism is discussed and implemented through development of a nursing care plan based on assessment of an autistic child. The assessment was performed using a version of Gordon's Functional Health Patterns, modified by the researcher to encompass all aspects of health concern for an autistic child.

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Preface

A five-year-old child enters the health center displaying multiple behaviors, including rocking back and forth, flapping his hands violently, and repeatedly echoing his mother's statements. Because such behavior is abnormal, it may suggest to the nurse that the child is experiencing excruciating pain or mental status changes related to electrolyte imbalance, hypoxia, or, possibly, some form of abuse. For this child, however, the behavior is normal and should not alarm health professionals to suspect acute physical impairment. The autistic child may simply be receiving a routine physical examination.

While this example would illustrate the more severe form of autism, the disorder may be manifested in many different forms. As children with autistic disorder are increasingly present in all patient-care settings, nurses must be prepared to distinguish normal from abnormal (Coucouvannis, 1997). Nurses must be aware of the diversity of behaviors that may accompany autism and be familiar with interventions to manage them. Methods of communication and interaction will need to be explored. Psychiatric nurses utilize these interventions as their primary treatment modality; community health and pediatric nurses incorporate them into the

plan of care; school nurses follow the child's progress and maintain consistency (Dychkowski, 2000). The nursing literature, however, is currently lacking in this area.

Individualizing a nursing care plan for a client's specific needs and abilities is fundamental to providing quality care. Regardless of a client's reason for a health-care visit, development of the nursing care plan will require sufficient information about the health history, co-existing conditions, and interventions used to treat those conditions in order to determine their effect on treatment of the current problem. Autistic disorder is one such condition that has massive implications for planning nursing care, particularly in children. Nurses must be knowledgeable about typical clinical manifestations of the disorder, observing and planning for these in the initial assessment. The planning of subsequent interventions should be directed by these findings. The purpose of this study was to gain insight into the behaviors of one autistic child and compare these findings to the existing literature. A modified version of the well-known Gordon's Functional Health Patterns was employed as an assessment tool. From these findings, a nursing care plan was developed, one which identifies nursing diagnoses, goals, and interventions to be used when caring for an autistic child.

The following example of a more common disorder illustrates the necessity of individualizing nursing care. Diabetes mellitus is a disorder that has a profound influence on a patient's plan of care, regardless of his or her reason for seeking medical attention. When a diabetic patient is hospitalized for a fractured hip, the

nurse will recognize that this patient will require certain interventions that other orthopedic patients may not require. The diabetic patient will need more frequent and more thorough assessment of perfusion in the lower extremities, more attention to foot care, special attention to wound healing if surgery is required, dietary considerations, finger sticks to assess blood glucose level, and insulin administration as ordered. Since autism is also a disorder that affects many aspects of a patient's life, the nurse must consider the implications of this disorder when planning care.

Chapter 1

Introduction to the Nursing Process

Before further discussing the implications of autistic disorder in individualizing nursing care, it is necessary to describe the nursing process and the development of a care plan. The nursing process, which was designed by the American Nurses Association (ANA) in 1973 and revised in 1998, borrows many ideas from the interdisciplinary scientific method (American Nurses Association, 1998). Sometimes referred to as the Standards of Care, the nursing process identifies six steps that a nurse must follow when caring for a client. Step One, Assessment, involves obtaining as much information as possible about the client, including subjective and objective data. Step Two, Diagnosis, is the analytical aspect of examining the data and identifying health concerns. The North American Nursing Diagnosis Association (NANDA) has approved 150 nursing diagnoses for use in clinical practice (Ackley & Ladwig, 1999). Step Three, Outcome Identification, involves identifying expected outcomes for the patient. The nurse collaborates with the patient, family, and other health care providers in formulating appropriate,

realistic, and measurable goals. Step Four, Planning, is the phase of developing a plan of care that lists interventions to meet the goals. The plan must be individualized to the patient's abilities and needs. Step Five, Implementation, encompasses the execution of all activities listed in Step Four. These actions help the client to meet the expected outcomes. Step Six, Evaluation, is the final stage in the nursing process. In this step, the nurse determines the patient's progress in meeting his/her goals (American Nurses Association, 1998).

Chapter 2

Literature Review of Autism Research

Though very little is available in the nursing literature regarding autism, research in other disciplines offers a valuable guide from which nursing considerations can be determined. Most of the research discussed here was obtained from educational, psychological, and medical journals.

Defining Autistic Disorder

While historical records have described individuals with autistic tendencies for centuries, the disorder was not given a name until 1943 when Leo Kanner identified it as *autism* (Mesibov, Adams, & Klinger, 1997). Kanner defined autism as “immersed within oneself,” with social isolation being the primary feature of the disorder (Mesibov et al, 1997, p. 5).

Autistic Disorder is currently described in the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM IV), as a disorder characterized by “impaired development in social interaction and communication and a markedly restricted repertoire of activity and interests” (American Psychiatric Association,

1994, p. 66). There are varying degrees of impairment with a diverse range of manifestations. According to the American Psychiatric Association (APA), epidemiological studies indicate that approximately 2-5 per 10,000 children have autism, with four out of five being male (1994). Though no formal surveys have proven such, many researchers propose that the prevalence rate has markedly increased since 1994.

In “The Autistic Dimension,” an article published in *Lancet* in 1991, researchers analyzed the distinction between autistic disorder and other Pervasive Developmental Disorders (PDDs). The latter group of disorders is described as featuring a “triad of social, language, and behavioral impairments” (The Autistic Dimension, 1991, p. 1192). Also included in the PDDs are Rett’s Disorder and Asperger’s Disorder. Rett’s Disorder can be distinguished from autism in that it affects more females than males, and involves more severe physical and mental retardation (APA, 1994). Asperger’s Disorder differs from autism in the more advanced language development present with this disorder (APA, 1994).

Possible Etiologies

Many factors have been blamed for the development of autism. Goldberg, Szatmari, and Nahmias (1999) replicated brain studies to examine possible structural differences. Their findings indicated enlarged brain size (most obvious in the temporoparietal region) and decreased size of the posterior corpus callosum. Candidiasis and certain food allergies (particularly gluten/casein intolerance) have been suspected in the development of autism (Adams & Conn, 1997). Twin studies

have suggested a strong genetic influence in neurobiological disorders, including autism (Tanguay, 2000). The following have also been suspected as etiological factors: the Measles, Mumps, and Rubella (MMR) vaccine, oxygen deprivation, exposure to drugs and alcohol, exposure to lead, phenylketonuria (PKU), encephalitis, and congenital rubella (Janzen, 1996). Many of these hypotheses have been tested, but findings have been inconsistent and unreliable.

Clinical Manifestations

Autism is manifested uniquely in each child diagnosed with this disorder. Some autistic children exhibit overt rocking behaviors and no language development, whereas others have more typical behavior patterns with mild language delay. Researchers have identified many signs and symptoms commonly seen in children with autistic disorder, but these must be considered individually; each autistic child will exhibit a unique set of these characteristics. "Autism . . . for people with special communication needs," published in *American Speech, Language, and Hearing Association (ASHA)*, lists characteristic symptoms of autistic disorder (1994). These are divided into four major categories of impairment: sensation, development of motor skills, communication skills, and social skills. Table 1 lists specific behaviors that are frequently associated with autistic disorder (ASHA, 1994).

Researchers have found that people with autism often perform better on visual-spatial tasks than on verbal tasks (Mesibov et al, 1997). This was supported by Sandberg, Nydyen, Gillberg, and Hjelmquist (1993) in their study of the cognitive profile in infantile autism. They used the Griffiths Mental Development Scale to

Table 1: Clinical Manifestations of Autistic Disorder

Abnormal responses to sensations	Delayed development of motor skills	Poor communication skills	Under-developed socialization
<ul style="list-style-type: none"> ▪ Poor attention to sights and sounds ▪ Withdrawal from sight, sound, or touch (lack of eye contact and facial responsiveness, indifference to or dislike of affection and physical contact) ▪ Inappropriate smelling, licking, or staring ▪ Self-stimulating movements (rocking, hand-flapping, or finger-flicking) ▪ Hyperactivity or hypoactivity 	<ul style="list-style-type: none"> ▪ Problems with large muscle skills (crawling, walking, or running) ▪ Problems with small muscle skills (grasping, using small objects, speech) ▪ Apraxia (difficulty controlling voluntary movements) ▪ Clumsiness (awkward hand/finger movements, walking on tiptoes) 	<ul style="list-style-type: none"> ▪ Totally absent language ▪ Immature grammatical structure ▪ Inability to name objects ▪ Inability to use abstract terms ▪ Inappropriate speech rhythm or inflection ▪ Lack of appropriate nonverbal communication such as facial expressions and gestures ▪ Poor understanding of the names of common objects and actions ▪ Difficulty understanding and using pronouns ▪ Echolalia ▪ Difficulty communicating basic wants and needs ▪ Difficulty asking and answering questions 	<ul style="list-style-type: none"> ▪ Inappropriate social interactions ▪ Inappropriate emotional behavior such as giggling, laughing, anger, tantrums, crying, or aggression for no known reason ▪ Inappropriate or unusual use of or attachment to objects ▪ Resistance to changes in routine ▪ Rituals or repetitive and unusual motions ▪ Failure to develop cooperative play and friendships ▪ No fear of real dangers

assess 70 children with autism and found peaks in motor and visual-spatial skills, and troughs in verbal and practical reasoning areas. The children also performed better on tasks with a clearly defined solution and little social contact than on skills requiring imitation and creativity. For example, many children scored very high in putting together jigsaw puzzles, but very low in drawing a picture of a man (Sandberg et al, 1993).

Mesibov and colleagues (1997) asserted that many children with more severe forms of autism exhibit signs of hyperactivity, impulsive/aggressive behavior, self-injurious behavior, abnormal eating patterns (picky eaters), and/or disturbed sleep cycles. A formerly popular, but since-disproved theory alleged that these autistic manifestations stem from cold, detached mothers and, therefore, autistic children remain detached from caregivers. In response to this theory, Peter Tanguay, M.D. (2000), identifies in his article "Pervasive Developmental Disorders: A 10-year Review" that autistic children do seek proximity and attachment to their caregivers, but they do not engage in attention-sharing behaviors. According to Tanguay, they often fail to show joint attention, neglecting to focus with another person on an object; because of this, autistic children generally do not point to objects. Tanguay also states that many autistic children do not develop a theory of mind, "an understanding that people have minds that differ from their own and that one can learn from others by reading their social signals and listening to what they say," (p. 1083, 2000). These deficiencies lead to a failure to understand social rules of communication (Tanguay, 2000). Calloway, Myles, and Earles (1999) more

specifically described an autistic child's use of communication as "a way to request objects or to control the behavior of others rather than as a means for social initiation."

Abnormal play behavior is frequently observed in children with autistic disorder. Most autistic children rarely engage in pretend play, indicating a deficit in representational thought (Rettig, 1994). Some autistic children exhibit more repetitive manual manipulations and oral contacts with toys than do their normally developing peers. Researchers have noted that many autistic children play with only a few favorite toys and neglect to spend time learning to enjoy new ones (Rettig, 1994).

Feeding difficulties are very common with autistic children. An article in *Nursing Times* discusses the nutritional problems of one child with the most severe form of autism (Kinnell, 1983). The parent reported that, in a tantrum, the infant had refused the breast and had to be bottle-fed. She eventually progressed to finger foods. Even at this early age the child vomited before, during, and after meals. She refused foods much of the time and often required tube-feedings. She also exhibited marked self-injurious behavior including head-banging, eye-poking, biting, trichotillomania (pulling her hair out), and scratching. Health care providers were presented a child with severe nutritional deficits, alopecia, dental clearance, marked dehydration, and a diagnosis of anorexia nervosa (Kinnell, 1983).

Autism is best described by parents, who experience the constant, global effects of the disorder. "He just lost his glow," one parent described as she recognized

the onset of autistic disorder. Barry Kaufman suspected that his child was deaf, when he, in fact, had autism (Kaufman, 1994). The child had seemed completely unaware of his surroundings, not responding to vocal stimuli or other environmental noise. Kaufman recounts “ . . . he slipped behind an impenetrable wall; he seemed at peace, fascinated by a world that none of us could grasp” (1994, p. 16).

Diagnosis

Autistic disorder is diagnosed based on observation of behavioral manifestations. It is not a behavioral, emotional, mental, or conduct disorder, but a description of symptoms (Shriver, Allen, & Mathews, 1999). Identification of various combinations of these symptoms is essential to a diagnosis of autism. Kanner’s Criteria served as the original tool for diagnosing autism. Leo Kanner identified three main areas of impairment: social development, language development, and adaptability (Mesibov et al, 1997). These categories have been adopted by the DSM IV, the current source of criteria by which a diagnosis is made. The APA has more clearly defined the specific requirements that must be met within these categories. At present, a child must meet the following criteria to be diagnosed with autism (APA, 1994):

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
 - (1) qualitative impairment in social interaction, as manifested by at least two of the following:

- (a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 - (b) failure to develop peer relationships appropriate to developmental level
 - (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, pointing out objects of interest)
 - (d) lack of social or emotional reciprocity
- (2) qualitative impairments in communication as manifested by at least one of the following:
- (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - (c) stereotyped and repetitive use of language or idiosyncratic language
 - (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
- (3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

- (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
 - (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 - (d) persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder (APA, 1994, p. 70)

Early diagnosis is essential. Jennifer Humphries (1998) asserts that an early diagnosis allows autistic children to achieve their full potential. Cann (2000) suggests that early detection positively impacts the child's development and reduces stress for parents.

Interventions

Once the diagnosis is made, a primary concern of parents and health-care providers is adopting an intervention strategy to meet the unique needs of the child. Hundreds of intervention programs have been developed, all with the objective of achieving some degree of normality. Basic principles should be considered when

choosing an intervention program. The following discussion is by no means an exclusive list of options, but is rather a select variety of strategies to illustrate the basic principles to consider.

Consistent longitudinal intervention is a fundamental component of therapy for an autistic child. The UCLA Young Autism Project (YAP) is a classic example of consistent, longitudinal treatment (Gresham, Beebe-Frankenberger, & MacMillan, 1999). This program utilized simple commands and differential reinforcement to promote development of socially acceptable functional behaviors. Aggressive, self-stimulatory behaviors were ignored and alternative behaviors were reinforced. The children received intervention every day for three years, 40 or more hours each week. Nearly 90 percent of the children receiving treatment showed improvements in intellectual functioning and were placed in less restrictive school environments (Gresham et al, 1999).

Windsor, Doyle, and Siegel conducted a quasi-experimental longitudinal study to assess an autistic individual's progress in language development over time (1994). They studied their intervention plan on an autistic female from age ten to age 26. Variable aspects of speech and written language, including quantity of words in vocabulary and number of spontaneous verbalizations, were examined to measure the effectiveness of a long-term communication intervention. The subject progressed from mutism to two-word spoken sentences and five-word written sentences with grammatical errors (Windsor et al, 1994).

Strain and Hoyson (2000) studied the effects of an intensive, individualized, family-oriented intervention program, implemented over nine years, on enhancing social skills of six autistic children. Involvement in the program, Learning Experiences: An Alternative Program for Preschoolers and Parents (LEAP), correlated with significant developmental gains in social interactions with caregivers and non-disabled peers (Strain & Hoyson, 2000).

Bellon, Ogletree, and Harn, elicited significant developmental gains for a child with autism in their implementation of repeated storybook reading with adult scaffolding (2000). The four-year-old child exhibited an increase in spontaneous speech and a decrease in echolalic responses at the conclusion of this repetitious, consistent program (Bellon et al, 2000).

Integration of autistic children with their normally developing peers, in conjunction with active measures to facilitate interaction, is an important component of intervention. Myles and Simpson found that simply placing the two groups of children in the same classroom does not sufficiently increase social interactions for the autistic children, but could be therapeutic in conjunction with an active intervention to facilitate interaction (1993). Kohler, Strain, Hoyson, Davis, Donina, and Rapp (1995) examined group-oriented contingency as an intervention that may be used in conjunction with the physical integration of children with autism and their normally developing peers. They found that offering a reward to the group, contingent on the completion of tasks by each member of the group, influenced peers to assist the autistic children with task completion in order that the group might

receive its reward. Richard Simpson (1993) recommended that, if school personnel regard the general education program inappropriate for a child with autism, then the school should seek maximum opportunities to integrate that student with normally developing peers.

Incorporating technology for visual and auditory prompting strengthens the efficacy of an intervention program. Bainbridge and Myles implemented a program whereby priming via videotape was used to introduce toilet training to a child with autism. The videotape familiarized the child with using the toilet and encouraged him to initiate toilet use. The program was effective in increasing initiations of toilet use and decreasing wet and dirty diapers (1999).

Hagiwara and Myles examined the effectiveness of a multimedia social story intervention in assisting autistic children to learn social skills (1999). Three autistic elementary school students participated in a computer-based interactive program to facilitate the learning of hand washing. All three children demonstrated significant improvement from their baseline abilities, and generalized the skill to settings not directly addressed by the program (Hagiwara & Myles, 1999).

Tabor, Seltzer, Heflin, and Alberto used an audiocassette player to deliver verbal prompts to a 12-year-old autistic student as a method of facilitating independent task completion. The student performed tasks using the cassette player for prompting until the sequence was internalized; the student then performed without using the assistive device (1999). The program increased the autonomy of the student in completing tasks, and decreased the need for teacher-guidance.

Communicating with autistic children on their level of understanding is an integral component of intervention. A study conducted by Violette and Swisher examined aspects of communication that influenced one autistic child's use of echolalic (imitative) speech. For example, the mother says, "Hi, Adam, how are you?" and the autistic child says, "Hi, Adam, how are you?" This type of speech is considered to be nonfunctional (1992). The researchers examined the effects of two variables on the production of immediate verbal imitations, or IVIs (the basic component of echolalic speech): the child's familiarity with the words and the communicator's style of directiveness. The researchers determined that the combination of a highly directive style of communication and less familiarity of the words used influenced the child's use of IVIs (Violette & Swisher, 1992). In using words familiar to the autistic child and communicating in a less directive manner, a parent is more likely to elicit understanding and functional responses.

Barry and Samahria Kaufman implemented a highly effective intervention program with their autistic son, Raun. The program, which gained publicity and was later named "The Option Process," outlined three important features of intervention:

1. Demonstrate (with sincerity) approval and acceptance underlying every approach.
2. Offer a motivational/therapeutic experience. Entice the child into the outside, understanding that, ultimately, he must motivate himself.
3. Develop a teaching program simplifying every event into small digestible parts. (Kaufman, 1994)

Barry and Samahria Kaufman refused to force their child into “normal behavior.” Instead, they accepted him on his level and established communication in a way that Raun could understand. They joined in his “autistic behaviors” and rocked or pinned alongside him (Kaufman, 1994). This intimate sharing of Raun’s world allowed the Kaufmans to show him that they accepted him, and enabled them to work with him in developing language at his pace. By adulthood, Raun had acquired verbal and written language and was functional in society (Kaufman, 1994).

The Kaufmans’ course of therapy illustrates an important component of intervention: progressing at the child’s pace. Raun was the leader in his therapy, and his interest, improvement, and motivation determined the progression of the program (Kaufman, 1994). Cognitive Behavior Management (CBM) is a technique that shifts the locus of control from an external source to the individual for self-monitoring and self-reinforcement (Quinn & Swaggart, 1994). Results of studies examining the effectiveness of this technique revealed that newly acquired skills were generalized across different settings and situations, based on the individual’s ability to consistently self-regulate treatment (Quinn & Swaggart, 1994).

McClannahan and Krantz developed an intervention program based on this principle of progressing at the child’s pace (1999). They created a series of activity schedules, which are sets of pictures and/or words that cue an individual to perform certain tasks, engage in activities, or enjoy rewards. For example, the schedule may instruct the child to dress him/herself. In beginning to teach this activity, the parent would use a schedule with pictures only, and would rehearse the steps with the child

many times, gradually withdrawing assistance. The child would progress to performing the activity using only the pictures. Written words would then be added; once the child became familiar with the words, the pictures would be withdrawn. Eventually the schedule would be withdrawn entirely, and the child would perform the activity independently. As the child progressed, more detail would be added to the schedules and the child would acquire more and more skills (McClannahan & Krantz, 1999). The activity schedules and rewards should be individualized to the child's pace, preferences, and level of functioning.

Activity schedules incorporate another important concept into treatment, that of breaking large tasks into smaller, more manageable parts (McClannahan & Krantz, 1999). This concept is the fundamental principle of Applied Behavioral Analysis, or ABA (Maurice, Green, & Luce, 1996). ABA is a theory of intervention that focuses on a systematic method of teaching small, measurable units of behavior. ABA utilizes reinforcers to encourage behavior, and withdraws these reinforcers to eliminate problematic behaviors such as self-injury (Maurice et al, 1996).

Early intervention is essential for optimal outcomes. In her article "Autism: Progress and Priorities," published in *Lancet*, Kath Senior discussed the future of treatment and intervention for autistic individuals (2000). She asserted that current priority in autism research is early intervention. She acknowledged progress thus far in mandatory preschool screenings in many states and provisions for follow-up, but declared the need for further investigation of the effectiveness of early intervention. She recommended that treatment begin by two years of age, as many children have

shown remarkable improvement by age six when intervention was started in toddlerhood (Senior, 2000). Currently in progress is an attempt to identify signs of autism by eight to ten months of age. Geraldine Washington is conducting a longitudinal study in which she reviews home videos of autistic children and observes for indicators of autism at the earliest possible ages (Senior, 2000). Mesibov et al support this theory of the effectiveness of early intervention (1997). They claim that “the evidence is incontrovertible that early intervention approaches are very effective at increasing developmental gains for the children and improving the functioning of their families, and result in long-term increases in skill and adaptation,” (Mesibov et al, 1997, p. 95). In a review of eight early intervention programs, Mesibov et al discovered that children who received early intervention averaged IQ gains of approximately 20 points (1997).

The program for the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) emphasized the importance of parent and teacher involvement in the intervention process (Gresham et al, 1999). Training is available for the parents as well as the child; parents are encouraged to adapt the home to be consistent with therapy, providing opportunities for generalization of skills across different settings. The TEACCH program resulted in developmental gain for most participants by increasing the amount of time the child was exposed to treatment, through supplemental parent-led treatment in the home (Gresham et al, 1999).

Many proposed intervention strategies are controversial, ineffective, and/or unethical. Medication therapy is one such controversial option, but is commonly used to treat autistic disorder. Stimulants, antidepressants, antihypertensives, anticonvulsants, antipsychotics, anxiolytics, antihistamines, narcotic antagonists, beta blockers, and serotonin antagonists have all been examined for their potential benefits in treating autism. Health-care professionals and parents must be aware that, despite possible benefits, most of these medications do not have Food and Drug Administration (FDA) approval for use in child and adolescent psychiatry (Sweeney & Forness, 1998). Serious side effects experienced by children for many of these medications include seizures, cardiac complications, sedation, altered blood pressure, decreased immunologic functioning, involuntary motor activity, and psychologic dependence (Sweeney & Forness, 1998). “Best practice suggests that medications are most effectively used as adjuncts to positive behavioral programming, social skills training, and other mental health intervention programs with established efficacy,” (Sweeney & Forness, 1998, p. 147).

Facilitated communication is a potentially unethical intervention that involves the use of a human facilitator who assists the autistic individual by supporting his/her hands on a keyboard. The facilitator aids in typing sequential letters to complete a communicative statement (American Academy of Pediatrics, 1998). This method has been widely rejected because of the possibility (or probability) of the facilitator’s influence in the outcome of the communication. The American Academy of Pediatrics has also discouraged the use of Auditory Integration Training. This

program involves a screening for the autistic child to test for hearing sensitivities and then utilizes repeated exposure to computer-modified music to desensitize the individual to the sounds. Results have been inconsistent and have not demonstrated differences between autistic and non-autistic children (American Academy of Pediatrics, 1998). Claiming to follow a behavioralist approach, Ivar Lovaas proposed using aversive treatment, particularly electric shock, to normalize behavior. While possibly eradicating some undesired behaviors, this method does nothing to enhance social development (Kaufman, 1994).

Chapter 3

The Nurse's Role in Planning Care for an Autistic Child

Autistic disorder presents numerous implications for health care. As demonstrated in the literature review, families have numerous options for treatment. These can be confusing and overwhelming for parents, and may influence them to seek assistance from health-care professionals in making a decision. Though it is not in the scope of nursing to learn about all treatment options nor to initiate therapy for autistic children, it is good practice for a nurse to be aware of the basic principles that have proven to be effective components of intervention, and be prepared to offer educated advice. Through extensive literature review and discussion with a parent of an autistic child, the following have been identified as essential components of an effective intervention program:

1. A longitudinal, continuous approach
2. Integration of autistic children with normally developing peers, in conjunction with active intervention to facilitate interaction
3. Incorporation of technology for visual and auditory prompting

4. Communication on the child's level of understanding – using a less directive approach and words that are familiar to the child
5. Progression at the child's pace and according to the child's interest, preferences, and level of functioning
6. Catabolism of large tasks into smaller, more manageable parts
7. Initiation of intervention at an early age
8. Inclusion of parents, school professionals, and health care providers in therapy

As a patient advocate, the nurse must be supportive of the family as it chooses an intervention program. The parents have, more than likely, attempted many different intervention strategies and need reassurance that they are competent caregivers. Nursing support includes incorporating the intervention strategy into the plan of care. For a behavioral health nurse, this requires following the intervention plan as the primary treatment modality. For a community health or pediatric nurse seeing the child for an unrelated illness, the child's intervention strategies must be incorporated into the plan of care to maintain consistency of the therapy. For example, health-care visits should be planned around therapy sessions if possible, and communication with the child in the health-care setting should be consistent with the communication methods used in therapy. Davies (1996) found, in a study of 70 families, that a nurse intently involved in care of the autistic child significantly reduced stress experienced by the families.

Nursing Assessment

The nursing assessment should include an interview with the parent and a physical exam. This allows the nurse to obtain as much relevant information about the client as possible, and validate findings. In addition to obtaining information necessary in assessing a normally developing child, the nurse should include assessment of factors specifically relating to autism. This includes assessment of intervention strategies attempted and currently in use, special dietary considerations, possible incontinence, level of communication, effective methods used to communicate with the child, presence of functional and non-functional autistic behaviors, hypersensitivity to environmental stimuli, presence of sleep disturbances, non-verbal behaviors, interaction patterns, and caregiver role strain. According to Shriver, Allen, and Matthews (1999), the core domains of assessment include social competence, communication, behavioral variability, environmental influence, physical functioning/motor skills, play/leisure skills, educational/academic skills, self-help/independent-living skills, and general/vocational behavior. All domains should be assessed to identify actual and potential health problems, including assessment of the caregiver for competence in providing care and role strain.

To obtain the most accurate data, the nurse should consider the context of behaviors. A more thorough assessment would include observation on several occasions, if possible (West & Evans, 1992). A child's behavior in the health-care setting may be much different than at home, particularly if the child is ill. The child's unfamiliarity with the health-care setting, the change in routine resulting from the

visit, the physiologic effects of illness, and having a “bad day” will affect the data collected. Thorough discussion with the caregiver can provide information on discrepancies in behavior patterns.

Establishing rapport with the caregiver is an important component of assessment. The caregiver must feel that the health-care providers are trustworthy and are seeking the best care for the child. The nurse should assure the caregiver that all information related will be confidential and will be shared only with those involved in the child’s health care (West & Evans, 1992). This is essential for obtaining the necessary data from the caregiver.

Observation of typical autistic behaviors is essential in assessing an autistic child. Functional autistic behaviors include limited use of rhythmic movements as coping strategies and use of echolalia in learning language. Non-functional autistic behaviors include overuse of rhythmic behaviors, overuse of echolalia, ritualistic behaviors contributing to impaired adjustment to change, and self-injurious behaviors. The presence of autistic tendencies will significantly affect the plan of care.

Use of a comprehensive assessment tool is necessary for inclusion of all pertinent data. Assessment tools currently in use are not comprehensive in examining the child holistically, and are more specifically used to screen for autism. The Checklist for Autism in Toddlers (CHAT) is a questionnaire filled out by the parent and a health care provider at the 18-month well-baby check-up (Tanguay, 2000). The CHAT is a screening tool aimed at identifying children from 18-36 months of age

who are at risk for social communication disorders. The CHAT, developed by Dr. Simon Baron-Cohen, assesses types of play behaviors, use of imaginative play, and initiation of social interaction (Tanguay, 2000). The Childhood Autism Rating Scale (CARS) is probably the most widely used observational protocol for autistic children (Shriver et al, 1999; Maddox, T., 1997). This tool uses a four-point scale to rate behaviors on a continuum from normal to severely abnormal. Other popular observation tools include the Pre-Linguistic Autism Diagnostic Observation Schedule (PL-ADOS), used in diagnosing children under six years of age, and the Autism Diagnostic Observation Schedule, used in diagnosing children over six years of age (Shriver et al, 1999). The Gilliam Autism Rating Scale and the Autism Behavior Rating Checklist identify behaviors that may lead to a diagnosis of autism (Shriver et al, 1999).

Gordon's Functional Health Patterns is a method of assessment that examines an individual's health in eleven areas (Kozier, Erb, Blais, and Wilkinson, 1998). The eleven patterns are identified as: the health perception/health maintenance pattern, nutrition/metabolic pattern, elimination pattern, activity/exercise pattern, cognitive/perceptual pattern, sexuality/reproductive pattern, coping/stress pattern, sleep/rest pattern, self-perception/self-concept pattern, and role relationship pattern. This assessment guide approaches the patient holistically and gathers as much data as possible concerning health. For this project, the tool has been modified to question aspects of health that are a particular concern for autistic children (See Appendix A). This modification of Gordon's Functional Health Patterns specifically assesses the

presence of echolalia, special dietary considerations, incontinence, adaptability, sleep concerns, self-injurious behaviors, communication, and social interaction patterns, in addition to generalized questions included in the assessment tool. This assessment tool is recommended because it assesses all eleven patterns of health, approaches the patient holistically, and specifically examines concerns for an autistic child.

Identifying Nursing Diagnoses

Nursing Diagnoses are determined from information gathered in the assessment. A diagnosis of autism presupposes that a child may experience certain health-related concerns. Table 2 identifies nursing diagnoses that commonly pertain to autistic children. The diagnoses were identified from information gained in the literature review of autistic disorder and assessment of one autistic child.

Table 2: Nursing Diagnoses

Nursing Diagnoses for an Autistic Child
1. Impaired verbal communication
2. Impaired adjustment
3. Ineffective individual coping
4. Altered development
5. Sensory/perceptual alterations
6. Impaired social interaction
7. Risk for social isolation
8. Risk for injury
9. Risk for altered nutrition
10. Risk for constipation
11. Risk for diarrhea
12. Self-care deficit
13. Total incontinence
14. Sleep pattern disturbance
15. Risk for caregiver role strain
16. Altered family processes

These diagnoses are further developed with goals and interventions in Appendix B.

Identifying Goals and Planning Care

Goals are determined by the client's motivation, level of functioning, and support system. The nurse should identify the client's strengths and weaknesses, using information gained in the assessment, to formulate appropriate goals. Short-term goals are essential for autistic children and their caregivers (West & Evans, 1992). They provide specific improvement measures that progress toward the attainment of long-term goals. Furthermore, they allow the child and parent to gain satisfaction from achievement of these goals, and encourage further therapeutic measures. Goals must also be measurable, listing a date and time when they will be evaluated. Most importantly, goals must be individualized to the patient (West & Evans, 1992). They should not be selected from a list for individuals diagnosed with autism; rather, they should be formulated specifically for the client, considering his/her assessment data. (See Appendix B for goals identified for the subject under study.)

In planning care for an autistic child, the nurse must again refer to the assessment data for the client's functional abilities; these will determine the interventions that are appropriate for this child. Goals are prioritized according to health concerns for the child, with safety always being the first priority in planning care (West & Evans, 1992). Care for an autistic child who exhibits self-injurious behavior will focus on elimination of these behaviors as a first priority.

Specific communication considerations are necessary when planning care for a child with autistic disorder. The nurse should be aware that the child has limited receptive communication skills and responds best to short, simple, indirect requests with eye contact. The nurse must also consider that the child's language may be impaired and she/he should be prepared to assess the child's responses using other methods. For example, Fanurik, Koh, Harrison, Conrad, and Tomerlin (1998) determined in a research study that nurses overestimate the abilities of cognitively impaired children to use the numerical pain scale, a standardized assessment tool that rates pain on a scale of one to ten (one being the least amount of pain and ten being the worst pain ever experienced). Nurses working with autistic children must assess other indicators of pain, including change in behavior, presence of fever, and holding the part of the body in pain (head, ear, etc). Abstract or ambiguous language should be avoided. Autistic children are very literal interpreters of speech; for example, a nurse who says "we will inject the dye" may provoke anxiety in the child who is familiar with the word "die" (Vessey, 1988).

Considerations in physical examination should also be of concern to the nurse when planning care for an autistic child. Many children with autism are very sensitive to touch and often do not comply with a physical exam. Nurses must be sensitive to this fact and be as gentle as possible when examining the child. The child should be approached slowly and touched lightly, and touch should be avoided when possible. It may be necessary to have the parent hold the child during the exam, particularly for any invasive procedures.

Implementing the Plan of Care and Evaluating Its Effectiveness

Implementation of the care plan involves performing the prescribed interventions. Again, the nurse should refer to assessment data for specific considerations for the child. The communication and physical considerations listed above will be necessary when implementing care measures.

Goals are evaluated by reassessing the child for responses to the interventions. Nurses will determine if the goal was met, partially met, or not met. The findings are used to redirect the plan of care. If a goal were partially met or not met, the nurse might re-implement the original plan, allowing more time for change, or completely abolish the plan and use different intervention strategies. When interventions are not met, the parents and child will need support and encouragement to continue therapy. Parents should be reminded of their competence in caring for the child.

Chapter 4

Assessment of an Autistic Child and Development of a Nursing Care Plan

In order to examine the effectiveness of the methods of assessment and care-plan development recommended in this thesis, an autistic child was assessed via the modified version of Gordon's Functional Health Patterns and a suggested plan of care was developed (See Appendices A & B). After obtaining approval from Western Kentucky University's Human Subjects Review Board (See Appendix C), three evenings were spent with an autistic child and his mother. The child was a four-year-old male who had been diagnosed with autism at the age of two years and four months. He was a moderately high-functioning child; he exhibited some hand-flapping, but no self-injurious behaviors. His mother was extremely supportive of therapy and spent hours with him daily working one-on-one. The child's behaviors and communication patterns were observed, and an interview was conducted with the mother to obtain data for the assessment tool and recommendations suggested. The tool was very effective in systematically assessing the child using a comprehensive

approach. Sixteen nursing diagnoses were determined from the assessment data and were developed in a nursing care plan. The experience with the child was very positive in noting the effectiveness of the suggested method of assessment.

Chapter 5

Conclusions and Recommendations

The beauty of nursing is that each patient comes to us with a unique set of characteristics and health-care needs. There is no room for boredom when each client is seeking a different goal and requires individualized care to promote success. Autistic children represent a special population of clients who require comprehensive assessment regardless of the current health concern. Autistic disorder potentially affects many functional health patterns, and each client exhibits a unique set of these deficits; a nurse must be knowledgeable about these potential influences on health, and observe for these in the assessment. This presents a challenge to many nurses who are unfamiliar with the disorder and its impact on behavior, communication, and health. These nurses are unsure of what should be included in an assessment of an autistic child and nursing considerations that must be employed.

A version of Gordon's Functional Health Patterns modified to target potential problems of an autistic child is recommended for assessing the child with autistic disorder. This tool was standardized for all autistic children to aid the nurse in

gathering appropriate assessment data for all potential problems. The tool directs the nurse to assess each of the eleven functional health patterns, and specifically includes questions regarding typical autistic tendencies. This alleviates the impossible task of one's memorizing all necessary elements of assessment that must be included when assessing the autistic child.

The nursing literature is currently lacking in research on autism. This disorder has numerous implications for nursing care and needs attention from nursing researchers in order to provide practicing nurses with knowledge of the most effective strategies in working with autistic children. At present, nurses must draw from other disciplines to determine appropriate communication methods and behavioral interventions, but nursing research should more clearly delineate considerations to be made within the scope of nursing practice. The literature review for this project was primarily compiled using research from other disciplines, and nursing considerations were developed using this information. Future research should focus on experimental testing of nursing assessment methods and intervention strategies.

In becoming aware of autistic tendencies and typical strengths and weaknesses, a nurse must remember that each child diagnosed with autism will present a unique set of signs and symptoms. Each will respond differently to the various communication and behavioral intervention strategies. A diagnosis of autism should not result in treatment per standing protocol; each child should be assessed individually if one is to determine the most appropriate method of intervention.

Ideally, nurses should claim the view held by Barry and Samahria Kaufman regarding their autistic son:

Raun was a flower, not a weed; an adventure, not a burden. What others portrayed as an affliction, we began to hold as a gift . . . We would embrace all the wonder and individuality of our son. (Kaufman, 1994, p.47)

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Appendices

- A. Modified Version of Gordon's Functional Health Patterns Used to Assess an Autistic Child
- B. Nursing Care Plan For a Child with Autism
- C. Approval Letter from Human Subjects Review Board of Western Kentucky University

Appendix A

Nursing Assessment of a Child with Autistic Disorder

-Modified using Gordon's Functional Health Patterns

*Assessment of the child using information obtained from mother and nurse's observations of the child

Client's Initials KR Age 4 Sex M

Health Perception – Health Maintenance Pattern

Reason for seeking health care: *N/A*

Previous hospitalizations/surgeries: *tubes in ears @ 18 mos; ER visit for laceration of lip requiring sutures @ 3 ½ years*

What other health problems has your child had? *RSV as infant (not hospitalized), frequent ear infections as infant, lactose allergy, chicken pox @ age 3 ½ yrs*

Are immunizations up to date? *yes*

What things are done to manage the health of the child (annual MD visits, annual dental examinations, psychiatric services)? *ABA therapy QD at school, therapist visit once per week at home, well-child check-ups up to age 3, dental exams semi-annually*

Safety measures:

- Seatbelt: *booster seat and seatbelt*
- Childproofing devices (outlet covers, locks): *none*
- Home safety devices (smoke alarms, fire extinguishers): *both*
- Does anyone in the home smoke? *no*

Statement of client's general appearance: *Well-groomed, hyperactive four-year old of average weight and height.*

Allergies/reactions: *Lactose allergy – diarrhea, cramping*

Medications the client is currently taking: *none*

Erikson's stage of development: *Preschool*

Client's ability in meeting tasks of this stage: *Patient is delayed in meeting developmental task. Initiates play with self, but does not initiate play with peers. Does not engage in imaginative play.*

Other pertinent data: *Child was diagnosed with autism at 2 years and 4 mos of age.*

Nutrition – Metabolic Pattern

Special diet: *Dairy-free diet at present; formerly adhered to Gluten-Casein-Free diet (no starches or milk products)*

Supplements/Vitamins: *none*

Appetite: *WNL for age; does not like texture of fruits/vegetables; likes texture of juice, meats, cookies, chips, crackers; mostly eats finger foods*

Wt. loss/gain: *none reported*

How does the child indicate he/she is hungry? *Pulls mother over to cabinet (does not point); sometimes sits at the table; mother leaves finger foods on the table most of the time for snacks*

Does the child have periods of refusing to eat? *Not for extended amounts of time; some days he eats less than others*

How are these periods managed? *N/A*

Nausea/Vomiting/Diarrhea noted: *Diarrhea when milk products ingested*

Condition of oral mucous membranes: *pink, moist*

Dental condition: *good hygiene (as provided by mother), appropriate number of teeth present for age*

Skin:

-Warm: *yes*

-Dry: *yes*

-Cool: *no*

-Moist: *no*

-Other: *no evidence of bruises, scarring, or abrasions*

-Turgor: X supple firm fragile dehydrated other:

-Color: ☒ pink ☐ pale ☐ dusky ☐ cyanotic ☐ jaundiced
☐ other

Edema: *none*

Wounds/Incisions/Dressings: *none*

Skin problems (description and location): *none*

Elimination Pattern

Usual bowel pattern (continence of bowels and bladder, frequency of BM and urination):

☐ Toilet trained ☐ Potty chair ☒ Diapers
**mother has not yet attempted toilet training*

Problems with elimination: *none reported*

Abdominal distention/guarding/tenderness: *none*

Use of laxatives, anti-diarrheals: *no*

Nocturnal enuresis: *yes; incontinent at all times*

What words does child use to describe defecation/urination? How does child indicate he/she needs to eliminate? *eliminates in diapers; does not indicate need to void*

Activity/Exercise

Cardiovascular problems (murmurs, vascular disorders): *none*

Respiratory problems (asthma, obstructive sleep apnea): *RSV as an infant*

Cough/production: *none*

Problems with large motor skills: *no; some difficulty in coordinating, taking turns with playmates*

Problems with fine motor skills: *yes; holding pencil/crayon*

Apraxia? *some difficulty in coordination*

Activity code:

0 = total independence
1 = assist with device
2 = assist with person
3 = assist with device/person
4 = total dependence

Use above code to assess:

ADL status:

Feeding_0 – *but does not use utensils*
Dressing_2_
Grooming_2 (*teethbrushing*)
Bathing_2_
Toileting_4 – *mother changes diapers*
Other____

Mobility status:

Ambulation_0_
ROM_0 – *full ROM*

Left/Right Handed: *right*

Devices needed or used for assistance: *none*

Persons available for assistance in the home/school: *home – mother; school – teacher aids*

What activities does the child enjoy? What is the child's favorite toy(s)? *enjoys watching Barney movies, playing outside, taking a bath, playing hide & seek, playing chase with cousins; favorite toys are plastic letters (enjoys dropping them on the floor), and Barney toys*

Ritualistic behaviors (routine): *@ 2 yrs old, he began to line up his shoes before putting them on; described by mother as "picky" and "neat;"*

Rhythmic behaviors (rocking, hand flapping): *exhibits some stemming or hand-flapping when he becomes agitated (does not rock or spin things)*

Self-injurious behaviors: *none*

Other pertinent data: *hyperactive child*

Cognitive/Perceptual Pattern

Level of consciousness: *alert*

Oriented to person X place X time X situation X
**difficult to assess because patient does not communicate verbally, but reported to be A&O x 4 by mother*

Describe behaviors: *hyperactive; abnormal for age; does not become upset in the presence of strangers; affectionate toward mother; plays independently with self*

Hx of seizures: *none*

Problems with reflexes: *none*

Movement of extremities: *full ROM*

Senses:

Sight WNL Aid used: *no*

Hearing WNL Aid used: *no*

Smell WNL

Touch WNL

** somewhat heightened sensitivity of visual and auditory stimuli*

Does the child respond normally to sensations (hearing, sight, touch, taste, smell)?
Holds ears with loud or odd noises

Does the child display hypo- or hyper- activity? *hyperactivity*

Dizziness: *none*

Numbness/tingling: *none*

Chronic pain: *none*

How does child describe/report pain? *cries*

Methods of pain management: *Tylenol, Motrin*

Describe communication:

-Vocabulary (comprehension and use of labels): *limited; comprehends and uses only basic nouns and verbs*

- Grammatical structure: *one and two word sentences*
- Use of abstract terms: *when instructed by caregiver (i.e., say "HI")*
- Speech rhythm/inflection: *appropriate rhythm; flat*
- Use of nonverbal communication (facial expressions, gestures): *does not point to objects, but pulls caregiver to things he wants; smiles and frowns; sometimes uses facial expressions abnormally*

Primary language: *English*

Speech deficit: *impaired language development*

Echolalia: *uses as a means of learning language; functional*

Does the child display appropriate emotional behavior (giggling, laughing, anger, crying, aggression)? *Yes; has just begun to show excitement in the last 6 mos; does not show significant response to others' emotions*

Does the child display abnormal attachment to objects? *Yes – to favorite toys*

Does the child display a healthy fear of real dangers? *no*

Learning difficulties: *learning is very slow; instruction must be paced with the child's understanding and must be repeated many times*

Other pertinent data: *Child is an active learner. Learns best with repetition of verbal cues and some sign language. Utilizes Applied Behavior Analysis (ABA) as primary method of therapy. Must make child look at you during teaching.*

Sexuality/Reproductive Pattern

Does child understand physical differences between males and females? *No (mother does not think he does)*

Other pertinent data:

Coping/Stress Pattern

Fears/anxieties: *patient becomes anxious if someone runs up behind him to tickle him*

What stresses has the child experienced? *parents' divorce; mother reports the child is happier after the divorce once readjusted*

How does the child manage stress? *sometimes cries, tantrums*

How does the child react to change in routine? *sometimes cries, tantrums; adjusts well to some changes (not predictable)*

What does the child do for relaxation? *holds his favorite blanket as he goes to sleep at night*

Other pertinent data: *he becomes stressed when someone takes away a favorite toy*

Sleep/Rest Pattern

How many hours does the child sleep per night? *8-9 hrs, but gets up at least once per night*

Does the child take naps? *no* Length of naps and time of day _____

Is this adequate? *yes*

Factors affecting sleep/rest:

Fear of the dark, of monsters, of intruders: *none reported*

Nightmares: *wakes up crying sometimes (possibly nightmares)*

Night terrors: *(see above)*

Sleepwalks: *no*

Difficulty falling asleep: *no*

Awakens during the night: *yes, at least one time every night*

Where does the child sleep (crib, regular bed, Jr. bed, with parents, with siblings)?
alone in twin bed until he wakes up; then sleeps with parents

Bedtime rituals (include security items): *mother rocks him before he goes to bed; sleeps with security blanket*

Hx of sleep disturbances: *waking up at night*

Other pertinent data: *child is active during the day and does not appear to be deprived of sleep*

Self-perception/Self-concept Pattern

Describe your child. What is he/she like? *"He is loveable and is a good child. He plays well by himself and with his two cousins. He is very active and busy. It takes much repetition for him to*

learn new skills, but he has improved a lot, especially over the past six months."

Appearance (grooming): *Child is very clean, neat, and well-groomed.*

Description of non-verbal behaviors: *Uses facial expressions to show excitement, frustration, and anger. Manipulates toys appropriately. Pulls caregiver towards something he wants.*

Self-injurious behaviors: *none*

Other pertinent data:

Role/Relationship Pattern

What are present living arrangements? *Child lives with mother and stepfather. Stays with biological father one night per week.*

Who are significant people in the child's life? *mother, stepfather, biological father, grandparents, cousins, therapist, teachers*

Who is the primary caregiver of the child? *mother*

Does the child attend school/daycare? *attends a preschool program that does some therapy; integrates autistic and non-autistic children*

Siblings (gender and age): *none*

How does the child interact with siblings? *N/A*

How does the child interact with peers? *Exhibits parallel play; participates in active games (chase); does not play board games; exhibits difficulty in initiating communication*

How do peers interact with the child? *Cousins initiate play with the child; play chase with him; do not engage in two-way conversation*

Does the child have same-sex and opposite sex friends? *yes*

Are peers generally the same age as the child, older, or younger? *all of these*

Values/Belief Pattern

Cultural practices: *none significant*

Religious affiliation: *Christian; child attends bible school and goes to church on Sundays with his parents*

Other pertinent data:

****What do you recommend to or require of the nursing staff in planning care for your child?**

Be aware that he does not have well-developed receptive language. Use simple basic words (fewer words are better). Be cautious with touch. Autistic children are susceptible to sensory overload. Involve parents in care as much as possible – most knowledgeable about the child's specific characteristics and ways to manage them. Have caregiver to hold the child still while performing medical procedures – child will not remain still on his/her own. Do not depend on communication with the child for assessment data – caregiver is the best source of information. Signs and symptoms of illness often difficult to assess as child cannot communicate his/her needs – observe for fever, pulling at ears, change in behavior, etc.

Nurses: Identify nursing diagnoses and plan of care for each, using this assessment.

Appendix B

Nursing Care Plan for a Child with Autistic Disorder

- from information obtained in assessment using modified version of Gordon's Functional Health Patterns (** signifies diagnoses and interventions that do not apply to the subject under study, but that are potential problems/needs of an autistic child)

Nursing Diagnoses with Corresponding Goals and Interventions

Note: Goals should list a date and time in which they will be evaluated. However, for the purposes of this project, this was excluded as no interventions were actually implemented. Some of the interventions listed would be performed only by long-term caregivers, but should be addressed by acute-care nurses as well.

- 1. Impaired verbal communication r/t inability to verbally express thoughts, secondary to autistic disorder, as evidenced by limited vocabulary and minimal initiations of verbal communication.**
 - Pt will exhibit an increase in initiating verbal communication, and in the number of words used.
 - (a) Interview the parent or caregiver for suggestions on how to communicate with and care for the child.
 - (b) Review the patient's medications and administer as ordered.
 - (c) Maintain eye contact when communicating with the child.

- (d) Use simple, short, concrete sentences when communicating with the child.
- (e) Use minimally directive speech when communicating with the child.
- (f) Use language/words familiar to the child.
- (g) Use scaffolding to facilitate language development. Initiate verbal communication by encouraging imitation. Progress to prompting with fewer and fewer cues. Gradually withdraw assistance.
- (h) Reward attempts to communicate verbally. Praise and reward the child initially for verbal imitation. Use rewards preferred by the child. As the child progresses, withhold rewards until the child demonstrates increased use of verbal language.
- (i) Use audiovisuals to supplement teaching.
- (j) Consult speech therapy as ordered (Ackley & Ludwig, 1999).
- (k) Use touch as appropriate. Assess autistic child for tactile defensiveness (Ackley & Ludwig, 1999).
- (l) Provide anticipatory guidance for caregivers regarding expectations for realistic attainment of developmental milestones (Ackley & Ludwig, 1999).
- (m) Implement/maintain therapeutic regimen to provide consistency.

2. Impaired adjustment r/t decreased adaptability and insistence on routine, secondary to autistic disorder, as evidenced by tantrums.

- Pt will decrease number of tantrums in response to change of routine.

- (a) See interventions for Dx 1.
 - (b) Implement change in routine very gradually and assess child for acceptance of change.
 - (c) Allow time for the child to perform ritualistic activities (rocking, spinning, flapping) in the acute-care setting as a means of coping with anxiety-provoking situations.
 - (d) Keep the child's favorite toys at the bedside to provide security and comfort.
3. ****Ineffective individual coping r/t autistic disorder, as evidenced by ritualistic behaviors (rocking, spinning objects, self-injurious behaviors).**
- Pt will decrease use of ritualistic behaviors
 - (a) See interventions for Dx 1 and 2.
 - (b) Apply band-aids to all injection sites as preschoolers (and those at a preschool age level of development) fear a break in skin integrity (Ball & Bindler, 1999).
 - (c) Teach the child to express feelings appropriately: words, pictures, physical activities, gestures (Johnson, 1997).
4. **Altered development r/t social and language impairment, secondary to autistic disorder, as evidenced by lack of initiations for social contact and limited use of verbal communication.**
- Pt will exhibit an increase in initiating social contact.
 - (a) See interventions for Dx 1 and 2.

5. ****Sensory/perceptual alterations r/t increased sensitivity to auditory and visual stimuli, secondary to autistic disorder, as evidenced by flinching at certain noises considered to be within normal range for most individuals and distraction with certain visual patterns.**
- Pt will decrease flinching behaviors in response to auditory and visual stimuli.
 - (a) See interventions for Dx 1 and 2.
 - (b) Use a minimally stimulating environment during teaching.
6. **Impaired social interaction r/t impaired social development, secondary to impaired autistic disorder, as evidenced by minimal interaction with normally developing peers, minimal initiation for communication, and inability to engage in conversation.**
- Pt will increase interaction with normally developing peers.
 - (a) See interventions for Dx 1 and 2.
 - (b) Integrate the autistic child with normally developing peers when possible.
 - (c) When integrating the child with peers, assign a group task with a reward for task completion to facilitate initial interaction.
7. **Risk for social isolation r/t impaired social interaction, secondary to autistic disorder.**
- See goal for Dx 6.
 - (a) See interventions for Dx 6.

- 8. Risk for injury r/t lack of fear of normal dangers and self-injurious behavior (not applicable to subject).**
- Pt will remain safe and free of injury.
 - (a) Maintain a safe, therapeutic environment with constant supervision.
 - (b) Keep sharp objects out of reach.
 - (c) Apply protective devices as needed (helmets, mittens, arm braces) to reduce self-injury
- 9. Risk for altered nutrition: less than body requirements r/t pt is a “picky eater” and lacks variety in diet**
- Pt will ingest Recommended Daily Intake for age in each of the food groups 75% of the time.
 - (a) Assess for s/s of nutritional deficit: weight loss, underweight/height on growth curve, poor dental condition, weakness, abnormal heart rhythms, decreased urine output, decreased hemoglobin, and electrolyte imbalance.
 - (b) Administer multivitamins as ordered.
 - (c) Offer foods for which the child shows a preference.
 - (d) Prepare fruits, vegetables, and meats to a consistency acceptable by the child (pureed, liquid, ground, finger foods).
 - (e) Administer a dietary supplement as ordered.
 - (f) Serve fortified milk and juice.
 - (g) Assess weight at least once per week.

- (h) If the child refuses to eat at mealtimes, have finger foods accessible to the child between meals to eat at his/her will.
- (i) Decrease food odors, if possible, as the autistic child may have a stronger sense of smell.

10. Risk for constipation r/t minimal fiber and bulk in diet.

- Maintain normal bowel patterns: bowel movement every day.
 - (a) Include fiber, fruits, and vegetables into the diet to facilitate normal bowel patterns.
 - (b) Assess bowel activity and administer stool softeners if needed as ordered.

11. Risk for diarrhea r/t intolerance of dairy products.

- Pt will exhibit no episodes of diarrhea.
 - (a) Eliminate/decrease foods in the diet that cause diarrhea. If the food provides essential nutrients, obtain a substitute (i.e., substitute Lactaid for milk).

12. Self-care deficit: bathing, hygiene, dressing, grooming, feeding, and toileting r/t autistic disorder as evidenced by lack of independence in performing these activities.

- Pt will participate in self-care as instructed.
 - (a) Change diapers and apply moisturizing cream as needed.
 - (b) Initiate/continue teaching to promote self-care.
 - (c) Assist with ADLs while teaching to perform independently.

- (d) Break up large tasks into smaller, more manageable parts; progress as the child masters each step
 - (e) Maintain a routine in teaching new skills
- 13. Total incontinence r/t inability to communicate to caregiver the need to urinate/defecate, as evidenced by patient urinating and defecating in diapers.**
- Pt will increase initiation of toilet use and decrease wet and dirty diapers.
 - (a) See interventions for Dx 12.
 - (b) Initiate/continue toilet training.
- 14. Sleep pattern disturbance r/t increased sensitivity to environmental stimuli, as evidenced by waking up during the night.**
- Pt will sleep through the night without interruptions.
 - (a) Reduce daytime naps.
 - (b) Maintain a quiet, non-stimulating environment for sleeping.
 - (c) Allow the child to sleep with a security item (blanket, doll, etc).
- 15. Risk for caregiver role strain r/t caring for an autistic child.**
- The caregiver will exhibit competency in caring for an autistic child.
 - The caregiver will present no signs of depression.
 - The caregiver will demonstrate use of stress management and relaxation techniques.
 - (a) Observe for signs of depression in the caregiver, and refer for counseling if needed.

- (b) Teach stress management techniques including personal wellness measures.
- (c) Connect caregivers to community resources that offer respite care.
- (d) Consider home health as a long-term care option to minimize disruption of family processes.
- (e) Support and reassure caregivers. Encourage to vocalize feelings and to contact support groups such as the Autism Society of America.

16. Altered family processes r/t autistic child requiring constant attention, care, and therapy, as evidenced by scheduled therapist visit once per week, nightly sessions with mother, lack of relaxation time for mother.

- See goals for Dx 15.
- See interventions for Dx 15.

Evaluation

Goals are evaluated through reassessment of the child and caregiver(s). They are listed as *goal met*, *goal partially met*, or *goal not met*. Evaluation was not possible for this nursing care plan as no interventions were implemented.

Appendix C

WESTERN KENTUCKY UNIVERSITY
Human Subjects Review Board
Office of Sponsored Programs
104 Foundation Building
270-745-4652; Fax 270-745-4211
E-mail: Phillip.Myers@Wku.Edu

In future correspondence please refer to HS0196R, September 12, 2001

Leanna Walker
1654 Normal Drive, Apt. 12
Bowling Green, KY 42104

Dear Leanna:

Your research project, "*Nursing Considerations in Assessment of a Child with Autistic Disorder*," was reviewed by the HSRB and it has been determined that risks to subjects are: (1) minimized and reasonable; and that (2) research procedures are consistent with a sound research design and do not expose the subjects to unnecessary risk. Reviewers determined that: (1) benefits to subjects are considered along with the importance of the topic and that outcomes are reasonable; (2) selection of subjects is equitable; and (3) the purposes of the research and the research setting is amenable to subjects' welfare and producing desired outcomes; that indications of coercion or prejudice are absent, and that participation is clearly voluntary.

1. In addition, the IRB found that: (1). The child's assent form is waived in the interests of the research. Full signed informed consent of the parent/guardian is required following appropriate orientation by the PI. (2) Provision is made for collecting, using and storing data in a manner that protects the safety and privacy of the subjects and the confidentiality of the data. (3) Appropriate safeguards are included to protect the rights and welfare of the subjects.
 - a. Your research therefore meets the criteria of Full Board Review and is approved.
2. Please note that the institution is not responsible for any actions regarding this protocol before approval. If you expand the project at a later date to use other instruments please re-apply. Copies of your request for human subjects review, your application, and this approval, are maintained in the Office of Sponsored Programs at the above address. Please report any changes to this approved protocol to this office. A Continuing Review protocol will be sent to you in the future to determine the status of the project.

Sincerely,



Phillip E. Myers, Ph.D.
Director, OSP and
Human Protections Administrator

c: Human Subjects File 0196R
Dr. Deborah Williams

HSApprovalWalkerHS0196R